

## **INCREASING DONATION BY FOCUSING ON THE HEALTH CARE ENVIRONMENT: PROFESSIONAL EDUCATION**

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### **Introduction**

The past two decades have seen remarkable advances in the field of organ transplantation in the United States and world-wide. For example, data for the United States show that heart transplants increased from a total of 103 in 1982 to 2085 in 1990; liver transplants increased from 62 to 2656 and pancreas transplants increased from 38 to 549 during the same time period. Kidney transplants, which have a much longer history, increased from 5358 in 1982 to 9560 in 1990 (1).

In addition to increasing numbers of transplant procedures, the patient and graft survival rates are increasing with improved methods of organ preservation, matching procedures, and immunosuppressive therapy, particularly Cyclosporine. For example, 1-year graft survival following a heart transplant in the pre-Cyclosporine era was 62 percent whereas in 1989 the 1-year graft survival was 82 percent (2). Even greater increases in survival have been experienced in liver transplantation.

Clearly, organ transplantation has increased not only the length of life, but also the quality and productivity of life for many individuals. Yet the limiting factor in organ transplantation is the dearth of donor organs. As of March 1991, 18,200 patients were waiting for kidney transplants, 1960 were awaiting heart transplants, 1340 were awaiting liver transplants, and over 500 were awaiting pancreas transplants (3).

To get a sense of the potential donor pool, approximately 2.5 million people die annually in the United States, and of this number, an estimated 20,000 would qualify as medically appropriate donors (4). Yet, in 1990, only 4300 of these deaths actually resulted in organ donation (1). In the previous 3 years, the number of actual donors appeared to plateau at 4000. At the same time, approximately 25 percent of those patients waiting for extra-renal transplants die because an appropriate donor is never identified. Close to 50 percent of children waiting for extra-renal transplants die while waiting.

Increased traffic safety statutes (i.e., required helmets for motorcyclists, required seat belts, and child restraints), reduced number of alcohol impaired traffic fatalities, and the HIV epidemic have been suggested as potential contributors to

the plateau in numbers of donor organs experienced in the late 1980s. Still, there is a large discrepancy between the potential and actual donors in any given year.

Significant efforts have been made over the past several years to educate the public as to the significance of organ transplantation. Gallup polls (5,6,7) indicate that the majority of the public are aware of organ donation, but there has not been a concomitant increase in organ donors.

An effective organ donation system relies upon a broad based alliance of health care professionals and the general public. A positive attitude toward organ donation among health care professionals will promote a supportive hospital environment for organ donation; an informed public who have discussed organ donation with family members will be more likely to respond positively when approached about organ donation.

This paper will focus on the necessity of increasing the involvement of health care professionals in the donation process: what role they should play; how their personal attitudes influence organ donation; and what are possible methods of eliciting greater support for organ donation. This is an area where little literature has been published to date. However, what has been published provides us with some guidance to certain interventions which may contribute to the enhancement of organ donation rates.

The matter of organ donation raises complex emotional reactions for non-medical people and for medically trained people as well. Dealing with the issue of donation of organs forces us, as individuals, to confront our mortality, which is difficult for most of us. For health care professionals, the situation is complicated by other issues such as perceived liability considerations and a general discomfort with the notion of approaching the family of a brain dead individual to encourage organ donation (8).

There appear to be three main groups of health care professionals who may be involved at some level with organ donation. First, there are those who are already members of the transplant community, such as transplant physicians and surgeons, clinical transplant coordinators, and organ procurement coordinators. Of these health care professionals, the role of the organ procurement organizations' (OPOs) staff, specifically the organ procurement coordinator, deserves particular mention. These individuals receive specialized training in promoting organ donation through public and professional education; approaching families of potential donors about organ donation; managing the donor prior to organ recovery; and assisting with the surgical removal of donated organs. These coordinators are employed by federally designated organ procurement organizations which in all areas of the country provide the link between transplant centers and hospitals which have identified potential organ donors. Along with transplant surgeons and physicians,

these health care professionals form the front line of transplantation. Unfortunately, with the exception of the transplant literature, there are few references in medical literature about the services the organ procurement organizations and their staffs provide for donor families and the staffs of hospitals which refer potential donors. Generally, it is the role of these health care professionals to provide education about organ donation to key individuals within the hospitals; to assist with hospital review, revision, and execution of policies and procedures regarding organ donation; and to respond appropriately to hospital initiated donor referral calls.

At the second tier are those professionals whose roles bring them into direct contact with the transplant community. These include social workers, critical care physicians and nurses, trauma physicians, neurosurgeons and neurologists. These individuals, through increased knowledge and positive attitudes toward organ donation and transplantation, could have a significant impact upon the rate of organ donation. To encourage physician and nursing education and support, some suggest that credentialing boards for the various medical and nursing specialties should include questions related to organ donation and transplantation in their written examinations as a means of raising the importance of the issue. Others suggest that undergraduate medical and nursing curricula should include issues related to organ donation and transplantation (9).

There appears to be some agreement in the literature that the attitudes and behaviors of physicians have great importance in influencing the rate of organ donation (8,10). Yet there are a number of factors which cause physicians to be less aggressive in seeking organ donations (8,10). Nurses, in general, tend to be more willing to actively participate in the process of seeking organ donations, although there is a reluctance on their part to do so without the explicit support of physicians (10).

The third group of professionals include clergy, morticians, medical examiners, coroners, and attorneys whose roles, though not directly related to the organ donation and transplantation process, place them in positions to significantly influence individuals' attitudes and decisions related to organ donation.

How can we most effectively provide training to these myriad professional groups which will better prepare them to use their respective roles to positively influence the rate of organ donation? Clearly, each professional category requires an approach which is tailored to its respective role in the process. It also must be determined at which point and where or when in professional training the subject should be introduced, or whether there should be a continuum of training activities. How can we assess the effectiveness of this training by immediate and more long term measures? Are there key issues that must be addressed? Are they constant or do they vary from group to group?

One thing which appears to be true is that health professionals' attitudes are not unrelated to public attitudes. Therefore, we would expect that the greater the awareness of the importance of organ donation and transplantation on the part of the general public, the greater will be the interest on the part of the various related professionals. Professional education cannot, therefore, be totally separated from public education.

In the pages which follow, we examine the current literature related to professional education and training in organ donation and transplantation. We look at what is now being done, what has been done in the past, and what various investigators have suggested for future directions. From this analysis, we attempt to identify the key issues in professional education related to organ donation and transplantation, and to formulate some proposed recommendations for consideration.

### **Current State of the Art**

Research efforts by transplant professionals have focused primarily on issues such as management of immunosuppression, outcomes of transplants, etc. Some studies have estimated the actual organ donor potential in the United States (11,12). Continuing work is vital since it may provide a clearer picture of the discrepancy between actual and potential organ donors. Closer examination of this gap in similar settings may lead to further delineation of the specific barriers to organ donation (11).

Several studies have been undertaken to examine personal attitudes and knowledge about organ donation among health care professionals; attempts have been made to correlate these attitudes and knowledge to successful organ donation requests (13-15). Similar works have identified barriers in the organ donation process and have made recommendations to correct these deficiencies (8,16). These surveys begin to tell the story of the correlation between attitudes and commitment and successful organ donation.

While these studies are important, little specific information exists regarding successful components of professional education programs. Two unpublished surveys, one by Warmbrodt (17) for the National Task Force on Organ Transplantation and another by Politoski (18) for the National Kidney Foundation, have briefly summarized past activities related to professional education. In 1985, the National Task Force studying the status of organ donation and transplantation in the United States conducted a survey to determine ongoing professional education efforts. Distributed to OPOs, voluntary health organizations, professional associations that might be involved in organ donation and transplantation, and professional transplant organizations, the results from the respondents showed that almost all education about organ donation in the

professional community was being done by organ procurement organizations. The OPOs which responded indicated that informal inservice education, combined with occasional structured workshops and seminars, were the types of education they most frequently employed. Only 7 percent of the OPOs specifically mentioned medical staff presentations or grand rounds.

Sixty-seven percent of the OPOs surveyed indicated that they believed that physicians (particularly neuroscience physicians) were the audience least receptive to their educational efforts. When queried as to how education efforts were directed to a group that was not receptive, respondents were almost unanimous in stating that only a physician, particularly a transplant surgeon, could enlist the interest and cooperation of another physician. One-on-one physician meetings seemed to be the most useful forum for education.

Conversely, responding OPOs indicated that nurses were the most receptive audience for professional education programs and, as assessed by the OPOs, were already more knowledgeable about organ donation than other health care professionals. Yet 81 percent of the OPOs' education programs were presented to nurses, perhaps indicating that OPOs spend a great deal of time and effort "preaching to the choir."

Only 18 percent of the professional education programs had measurable goals and objectives. There was basically no consensus as to how to evaluate the success of the programs, although an increase in hospital referrals following the programs was mentioned frequently (17).

The National Kidney Foundation (NKF) study was conducted at the annual convention of the American Association of Critical Care Nurses in 1988. This study of fifty randomly selected nurses attempted to determine the effectiveness of existing training programs and to look at particular ways in which the National Kidney Foundation could effectively motivate nurses to become involved in organ donation. Seventy percent of the respondents of the NKF study had personally participated in approaching families about organ donation. Of those who had approached a family, 83 percent had received formal training related to donation prior to their participation. Classroom instruction had been received by 46 percent of all respondents; 83 percent of the training was conducted by an organ procurement coordinator. Components of training programs were varied and included at least one of the following: lecture, film/tape, discussion, literature, and role-playing. Although most nurses who had participated in training programs felt confident in being able to discuss donation with families, they related feelings of apprehension and discomfort in this role (18). These findings suggest that current education programs lack key components that would enable nurses to effectively influence organ donation. Further investigation of these programs is warranted.

Pervasive in the literature is an acute lack of knowledge of issues related to organ donation and transplantation among health care professionals (9,16,19,20). In a statement presented to the National Kidney and Urologic Diseases Advisory Board, Dr. Patricia Adams stated that "in an era of remarkable public awareness and unparalleled medical success, the medical profession itself is relatively uneducated about the essentials and successes of this new therapy (organ transplantation) and feels little general professional responsibility to procure organs" (21).

In a 1986-87 joint SEOPF-UNOS Survey of Professional Attitudes Toward Organ Donation and Transplantation (15) sent to professional staff at 176 transplanting hospitals in the United States, medical professionals manifested a positive attitude toward organ donation. However, they demonstrated a striking lack of knowledge about social issues and epidemiologic facts of transplantation. Twenty-four percent were unsure how brain death related to cardiopulmonary arrest, and 19 percent thought that withdrawal of support from a brain dead patient constituted mercy killing. Less than 20 percent knew the current graft survival rates for kidney, heart, or liver transplant, and only 8 percent could approximate the number of heart transplants performed in this country in 1985 (15).

Younger and associates (13) interviewed a sample of 195 physicians and nurses likely to be involved in organ procurement in an effort to determine their knowledge, personal concepts, and attitudes concerning brain death and organ donation. Only 35 percent of the respondents correctly identified the legal and medical criteria for determining death. Most respondents (58 percent) did not consistently use a clear description of brain death. Physicians in decision-making roles tended to be much more knowledgeable about these issues than other health care professionals, but the professionals' confusion about brain death criteria has tremendous implications for their involvement with organ donation. One-third of the participants in this survey had participated in transplant education programs. These individuals tended to be more knowledgeable about clinical and legal matters, but their level of understanding about brain death did not correlate with their having participated in such education programs.

A survey of medical and surgical residents at two large teaching hospitals regarding their knowledge, attitudes, practices, and experience with organ donation was conducted by Spital in 1989 (9). Thirty six percent of the respondents were not sure how to recognize a potential donor and 34 percent were not sure who to contact if a donor was identified.

In another survey of family practice residents from five midwestern training centers (19) nearly one-half of the respondents stated that they knew very little about organ donation and would not know how to initiate the process. There were concerns related to premature declaration of death, concern for family feelings, and the cost-benefit ratio of transplantation. A majority of the respondents in both

surveys indicated strong personal support for organ donation. Lack of knowledge of donation criteria, and other issues expressed here, need to be addressed in order to gain commitment from an already supportive population.

A large scale survey of ICU staff complemented by public and professional opinion polls was conducted in England in 1987 (22). Like Gallup Polls conducted in the United States, the majority of the public were supportive of organ donation. When queried as to whether the topic of organ donation had been discussed with their general practitioner, only 2 percent responded positively, but over 50 percent indicated willingness to donate organs. There was also overwhelming support for organ donation among physicians, with no difference in attitudes between general practitioners and hospital based specialists. Physician groups also agreed that organ donation and transplantation should be given considerable prominence in undergraduate medical training (22).

In this same survey, the intensive care staff were asked to indicate which of nine different factors limited organ donation. These factors included dislike of increasing a relative's distress; reservations about brain death criteria; lack of experienced clinicians familiar with brain death criteria; resentment about the time, effort, and cost involved; lack of training in approaching families; adverse media publicity; unfortunate experiences with transplant team members; lack of written policies; and general distaste for procedures involving organ recovery. While no one factor was unanimously identified, the possibility of increasing a relative's distress and lack of training in the approach to families both rated highly as disincentives to organ donation. Nurses in particular felt that lack of training in approaching families and lack of written policies hindered donation (22).

Malecki and Hoffman (14) examined the level of discomfort regarding organ donation among intensive care nurses and its effect on obtaining consent for organ donation. Of 124 nurses who responded, 93 percent indicated that they were aware of criteria for organ donation. Only 33 percent said they had ever been in a position to approach a family for consent, and of these, only 29 percent actually did approach a family. Of families who were approached by a nurse who had a self-perception of confidence, 84 percent said yes, while 100 percent of the families approached by "uncomfortable" nurses declined to donate.

A 1990 survey performed by Stark (20) to look at how attitudes of nurses affect organ donation found that nurses were frequently the first health care professionals to recognize potential donors, but only 65 percent of those surveyed could correctly identify clear cut instances where patients were suitable potential organ donors. Both physicians and nurses were overwhelmingly supportive of donation, and families who were initially unsure of their decision eventually

consented to donation when the nurses and physicians appeared to favor it. In this study of 26 potential donors, six families were not approached about donation, with the main reason cited as "physician reluctance caused by fear of liability"

A recent study by Bidigare and Oermann (23) examined ICU nurses' attitudes toward organ donation and the nurses' knowledge of organ donor protocols. As in previous studies, the majority (94 percent) of nurses were supporters of organ donation. However, only 51 percent had made provisions to donate their own organs, and only 67 percent would encourage family members to do so. Race seemed to correlate with nurses' attitudes, with Black and Asian nurses being less supportive of organ donation than White nurses. However, the small numbers in the survey made it impossible to draw any firm conclusions.

In this same study (23), nurses who had higher knowledge levels were more positive toward organ donation as evidenced by their personal decisions, their willingness to influence families, and the degree to which they would choose to participate in an organ recovery. The survey indicated that the nurses' knowledge base increased with participation in the care of an organ donor and that this expanded knowledge base enhanced positive attitudes toward donation (23).

Perhaps the most extensive look at attitudes of health care professionals was a study performed by Prottas and Batten (8). Neurosurgeons, intensive care unit nurses, directors of nursing, and hospital administrators were surveyed in order to determine their level of commitment to donation, to identify how the groups differed in their level of commitment, and to examine the sources of those differences. While neurosurgeons nearly unanimously indicated support for donation on a personal level and said they were confident of the criteria to determine brain death, nearly 60 percent said that there could be a conflict between treating a patient whom they believe is dying and protecting organs which could be transplanted. Many expressed reluctance to approach families about donation; they were concerned about the time involved in the process and potential legal liability. Neurosurgeons who believe that organ procurement is a professional responsibility are less concerned about interactions with families, time demands, and the threat of legal liability.

ICU nurses surveyed in this study (8) expressed support of organ donation with a strong conviction that organ donation helps families through the grieving process. Nurses expressed two areas of particular concern -- their lack of confidence in physicians' awareness of accurate criteria needed for the determination of brain death and the potential conflict between treating a dying patient and management of organ donation. The most supportive groups of ICU nurses were those found in large ICUs in teaching hospitals. Many of these nurses who had been involved with potential organ donors perceived physicians to be very supportive of donation.

Combining physician support with nurses' belief that organ donation is a professional responsibility tended to minimize apprehensions and conflicts of nurses surveyed in this study.

Prottas and Batten found hospital administrators supportive of organ donation in general and most supportive when they believe the physicians in the hospital are supportive. Directors of nursing demonstrated attitudes similar to nurses and other hospital administrators (8).

### **Summary and Conclusions of Existing Studies**

Almost exclusively, the responsibility for identification and referral of potential organ donors falls to health care professionals employed in a hospital setting. Surveys of these groups bear striking similarities. They are personally strong advocates for organ donation, but the level of their commitment in this process is quite dependent on their attitude of professional responsibility, the measure of support for organ donation they perceive from their peers and other health care professionals, and their knowledge of the process. Unfortunately, survey data indicate that knowledge of the process is sorely lacking. Health care professionals are relatively unaware of criteria for organ donation and how to make a referral (9, 19). They have significant concerns regarding potential conflicts of interest, liability issues (20), family responses to requests for organ donation, cost-benefit considerations (19), and perceived commitment of personal time and energy required of them during the donation process (8). Among all groups, physician support for organ donation appears to be the most critical factor, so these issues most certainly need to be addressed in professional education in order to elicit greater cooperation and commitment to organ donation.

#### **Current Practices**

##### **Organ Procurement Organizations**

Organ procurement organizations recruit employees who for the most part have health care professional backgrounds. Most are nurses with critical care experience but who frequently come to the organization without prior experience in organ donation. In addition to on-the-job training, many organ procurement organizations send new employees to a 1-week training program conducted twice a year by the North American Transplant Coordinators Organization (NATCO). Another 4-day workshop on developing skills to approach families about donation, and teaching these skills to others is also highly recommended by many organ procurement organizations. This particular workshop has been conducted at least annually by Margaret Verble and Judy Worth.

Organ procurement organizations' staff spend considerable time providing public and health care professional education about donation. Again, little data is

available regarding the successful components of these programs, specific content, to whom they are directed, or how to measure their effectiveness.

In an attempt to systematically solve the organ donor shortage, a 2-year research-based demonstration project has been initiated with four organ procurement organizations. The project is directed by the Partnership for Organ Donation. It is the belief of the Partnership, shared by the four organ procurement organization sites, that organ donation will increase when better donation processes are implemented within hospitals and the public becomes more committed to donation through effective public education programs.

The Partnership's strategy for improving donation within the hospitals is threefold: first, to focus on the key hospitals which have the greatest potential for organ donation; second, to identify key individuals within the hospital who are most likely to be involved with donation and to develop with them a team approach to donation; third, to focus on the families' needs in the critical care unit and to insure that the approach to families about organ donation is not initiated until the family members show clear indication that they understand their loved one has died (24). Research done as part of the Kentucky Organ Donor Affiliates (KODA) pilot project suggested that this approach to families had a significant effect on consent rates (11).

### **Health Care Professionals Within the Hospital Setting**

Brain death is central to organ recovery, so within the context of their work, neurosurgeons' support may be a critical component of a successful organ donation program. From survey data it appears that neurosurgeons' concerns about organ donation are mitigated by the feeling that involvement in seeking organ donation is a professional responsibility (8). Therefore, transplant professionals, in collaboration with the United Network for Organ Sharing (UNOS), have begun to work with national associations representing neurosurgeons. To date, an 8-minute video portraying the clinical assessment of brain death and a "neuro ruler" detailing criteria for organ donation have been made available to neurosurgeons. Resolutions supporting organ donation have been adopted and published by the Congress of Neurological Surgeons and the American Association of Neurological Surgeons. It remains unclear how these resolutions translate into action on the part of the individual health care professional.

All physician groups surveyed expressed some lack of knowledge or concern about some aspect of organ donation. If they are not confident of their knowledge or if their concerns are not addressed, then asking them to initiate organ donation poses a significant problem. Many of these concerns seem to be of a psycho-social nature, such as dealing with death and dying and how the discussion of organ donation affects a grieving family. Expectations that physicians are skilled in

dealing with dying patients and their families may be unfounded. Medical school education about death and dying is relatively new in the United States (25), and there is little consensus on teaching methods and course content. In a 1989 survey of medical schools, 51 of 111 respondents replied that death and dying was taught only as a module of a larger course; 30 respondents provided only one or two lectures on these issues during the first 2-years of medical school.

Hospital staffs are very comfortable with pursuing organ donation when the request is initiated by the family of the deceased. Taking this the next step, it could be hypothesized that if medical professionals perceive public acceptance and support for organ donation, they will be more inclined to participate. Aggressive public education campaigns may subtly influence health care professionals as well as the public. There is a body of literature which holds that individuals adopt behaviors which are congruent with what they perceive to be the norms of society. One might suggest, therefore, that if the norm of society is perceived by health professionals as a willingness to consent to organ donation, then there would be a greater willingness on the part of health care professionals to approach the families of brain dead individuals.

Reservations about approaching a grieving family about donation may result from a perceived conflict of interest. Tolle (26) states that primary care physicians must serve as advocates for their patients; but the role of requesting organ donation serves another patient -- the transplant recipient. She suggests that the solution is to have the formal request made by personnel not directly responsible for the clinical care of the potential donor. If this is in fact a true barrier, then the organ procurement community must reinforce their willingness, sensitivity, and experience to participate in this process. Physicians willing to initiate the donation discussion with families must be given adequate information and training in order to perform this task as comfortably and as confidently as possible. How this information and training are best imparted is not clear and needs further investigation.

Each physician must be clear about his or her role in organ donation. Like advanced directives, prior discussion with patients about organ donation from a supportive physician may have great influence on family decision-making. Information about donation should be readily accessible to all physicians, yet there is a paucity of information in the literature addressing the role of primary care physicians in organ donation.

Knowledge about criteria for donation, access to the organ procurement system, and successes of transplantation are details that can easily be provided by the organ procurement organizations at staff meetings, grand rounds, or one-on-one interaction. Greatest receptivity of this material may be achieved by introducing the topic through peer organizations. Transplant surgeons and physicians are often

effective educators in this area. The extent of legal exposure for physicians must be addressed through authoritative channels such as eminent judges or local bar associations. To ameliorate the heavy emotional toll which the organ procurement process exacts on those involved, feedback should be provided from transplant recipients as well as donor families.

Organ donation and transplantation ought to be addressed at every level of medical training. It should begin in medical school and be reinforced during house staff training. The UNOS education committee is currently completing a modular curriculum to be used by medical and nursing schools. Hopefully the importance of the subject matter will be reinforced by the inclusion of questions on credentialing examinations.

From the previous studies, nurses appear to be the strongest supporters of organ donation (8,14,20). Many have discussed donation with their families, and they sign organ donor cards in higher proportions than the general public (23). Most nurses feel that involvement in organ donation is a professional responsibility (8). To enhance the participation of nurses in the organ donation process, the National Kidney Foundation has developed a 1-day program "Making the Critical Difference" designed primarily for critical care nurses. The program recognizes critical care nurses as highly trained professionals whose feelings and attitudes affect their willingness to participate in the organ donation process. It addresses their concerns and allows them to discover the roles they can play in the process. The success of this program will be tracked over a 2-year period. To better understand the nurse's role in the organ donation process and to identify a profile of nurses most likely to participate in the process, a survey will be administered prior to the beginning of each workshop and at 6 and 12 months following the program. This information may prove very useful in identifying the training needs of nurses working in critical care areas.

Perceived support for organ donation among peer groups and other health care professionals appears to correlate strongly with willingness to participate in the organ donation process, and most health care professionals surveyed believe that physicians are the most critical link (8). Apparently a strong and consistent perception on the part of nurses is that physicians are not supportive of organ donation, despite numerous surveys that suggest the reverse. While nurses may perceive their role as one of facilitator in the donation process, they appear reluctant to do so without physician support. Other health care professionals such as hospital administrators and directors of nursing express strong support for the process if physicians are known supporters.

Believing that professional cooperation, especially among physicians, is vitally important to successful outcome of an organ recovery, a number of hospitals have created multi-disciplinary teams consisting of hospital administration, nursing

representatives, neuroscientists, trauma physicians, chaplains, and social workers to formulate mechanisms for identifying potential donors and notifying organ procurement organizations, to insure that families of potential donors are informed of their options regarding organ donation, and to provide adequate training for those involved in the request process (27-29). All hospitals indicated an increase in organ donation after initiation of such programs. A secondary outcome was the perception that the hospital staff are better informed about organ donation issues.

### **Role of Other Professionals**

Supportive roles of other professionals in organ donation need to be more closely examined. Surveys indicate that the public is frequently unaware of their religion's stand on organ donation (7). Active participation of the clergy in addressing this problem requires that they also receive accurate and timely information about organ donation.

Attorneys and funeral directors frequently counsel individuals about health care directives, and pre-need funeral arrangements. How can they best be encouraged to support organ donation?

### **Critical Issues and Questions**

We have identified a number of critical issues related to the roles of health care professionals in increasing organ donation, and educational efforts needed to enhance organ donation. Out of these statements, we will propose some recommendations for consideration.

**ISSUE I:** All of the studies which have been conducted to date suggest that the attitudes and behaviors of physicians are of crucial importance to the success of organ donation programs. Although nursing staff in hospital settings have demonstrated their willingness to approach families of potential donors, there is evidence that without the support and leadership of physicians, there is less willingness on the part of nursing staff to take an aggressive role in this regard. Therefore, it is suggested that training resources should selectively target physicians.

**Discussion:** Given that we know about the importance of physician attitudes in the process of organ procurement, a number of questions are raised and need to be answered. These include:

- Which specialists are most important to target? Studies point to the importance of targeting neurosurgeons, neurologists, intensive care

physicians, trauma physicians, and in certain cases, family practitioners, since these individuals are most often found to be caring for patients who are potential donors.

- Who should most appropriately conduct the training of physicians? What role should organ procurement organizations, national associations of OPOs, UNOS, etc., play in the training process? It has been shown that physicians respond better to training which is done by peers rather than by individuals who are non-physicians.
- At which point in medical training would such training be most effective: undergraduate level, graduate medical education, in-service education for practicing physicians, or all of the above? If at the undergraduate level, then in which parts of the curriculum should it be included (i.e., medical ethics, public health, critical care rotations, etc.)? Are there model programs that can be emulated?
- Should there be questions included on board examinations related to organ procurement and transplantation, or should the maintenance of licensure and/or board certification rely in part upon certification that there is a minimum level of knowledge related to organ procurement and transplantation?

Clearly an indepth discussion of each of these questions may give rise to a number of recommendations, and a variety of organizations or groups of individuals might logically be assigned responsibility for the implementation of such recommendations.

**ISSUE II:** The roles of the various professionals who are involved in the coordination of organ procurement and transplantation are not well defined, understood, or agreed upon by the transplant community, and by the medical community in general.

**Discussion:** Organ Procurement Coordinators are skilled in assisting with the process of requesting organ donation when a potential donor presents. These individuals, who often come from a nursing or physician's assistant background, are trained in the skills required to approach families of potential organ donors seeking permission for organ donation, and in the management of the donor prior to organ recovery. On the other hand, there are the critical care nurses, trauma care physicians, intensive care physicians, neurosurgeons, and neurologists who are providing care for the individuals who often become potential organ donors. It appears, in many cases, that identifying the respective roles of these professionals and promoting a team approach to organ donation may facilitate the process of organ donation and transplantation.

**ISSUE III:** Training and sensitivity as to the importance of approaching the families of potential organ donors must be institution wide, in addition to targeting individual health care professionals.

**Discussion:** Although, as noted above, the attitudes and behaviors of physicians related to organ procurement seem to play a key role in assuring positive outcomes, it is equally important that institutions, namely hospitals and their administrative structures, and related national organizations be sensitive to the importance of organ procurement. This calls for special efforts on the part of organ procurement organizations and others responsible for training, to target hospital administrators and boards of directors. Such training can be approached through increased liaison with hospital associations at the national and State levels. This would involve working with the American Hospital Association, and State hospital associations, in addition to individual hospitals. Questions which are raised in this regard include:

- What are the most effective ways to train boards of directors and hospital administrators?
- Who are the people who are most appropriate to conduct such training?

**ISSUE IV:** Federal and State policy makers who are involved in the formulation of public policy related to organ procurement and transplantation, many of whom are themselves trained as health care professionals, need to also be aware of the issues related to organ procurement.

**Discussion:** Federal and State policy makers are required to view issues from the perspective of fiscal, statutory, and regulatory considerations. As such, it is natural for these officials to view their roles as "guardians of the gates" rather than as facilitators. What can sometimes be short changed in the considerations of policy makers are the human dimensions of the problem and how it might be possible to creatively overcome barriers to the achievement of the desired objectives. Therefore, the organ transplant community must be mindful of the need to design strategies which will promote a high level of awareness on the part of policy makers as to the practical dimensions of implementing legislation in such a way as to result in effective organ procurement and transplantation programs. Again, the question as to how best to accomplish this training and sensitization arises. Also, who are the public officials and policy makers who should be most appropriately targeted in such training? One potential model for such training might be the series of State legislative workshops which were convened around the country in the late 1980s by the National Center for Health Services Research in which they assembled select legislators and high level government policy makers from a number of States to address issues involved in the response to the HIV epidemic.

**ISSUE V:** There are too few good studies which can serve to illuminate the subject of the shortage of organ donors to provide us with specific guidance as to the best approaches to professional training related to organ procurement.

**Discussion:** Further data accumulation and studies are needed before we can answer some of the key questions related to professional training in issues of organ procurement and transplantation. These include such questions as:

- How do professional attitudes and knowledge compare with public attitudes and knowledge related to organ donation and transplantation?
- Are there any comparisons that can be made of various approaches which have been taken to train undergraduate medical students in issues relating to organ donation and transplantation, and the relative effectiveness of these approaches?
- Are there certain OPOs whose professional training programs have succeeded in increasing the rate of organ donation within their respective regions, and if so, can we identify the elements which are responsible for this?

If these, and other questions could be answered, we would be in a better position to design appropriate and effective training modalities targeting health care professionals.

**ISSUE VI:** Issues of legal liability are often cited as reasons why health professionals, particularly physicians, fail to be more active in seeking permission for organ donation. Such questions as "who owns the donated organ?", "is the donor card valid?", "has brain death been properly diagnosed?", etc., are raised as being responsible for physicians' hesitancy.

**Discussion:** Since issues of legal liability appear, at least anecdotally, to be of real concern to health care providers, it may be important to look at actual experience to see if the perception is supported. It is important that the legal issues be addressed carefully and objectively so that there are factual answers for the above concerns. It may be necessary to design a study which would specifically determine the frequency with which litigation has been brought against physicians and other health care professionals in cases related to organ donation. Having answered this question with actual data, it would be possible either to support the perception or refute it.

**ISSUE VII:** Early studies suggest a number of attitudinal impediments on the part of physicians which deter the optimal recovery of organs. These include perceived conflict of interest, fear of liability, lack of current information about the process,

reluctance to spend the time necessary to work with the family of a potential donor, and the high cost of transplantation.

**Discussion:** Each of these attitudinal issues can contribute to the relatively low rate of organ procurement. Any recommendations for training, especially of physicians, must address each of these issues so that, where possible, these attitudes can be influenced in a direction which will succeed in improving the rate of organ donation. In terms of the issues of cost, for example, we must evaluate the cost of maintaining patients with end-stage organ failure as opposed to the cost of a transplant, with subsequent restored physical function.

**ISSUE VIII:** Perhaps OPOs should establish realistic annual goals for organ recovery based upon an accurate assessment of donor availability within their service area. This assessment and goal setting would also allow for evaluation of the success of professional education efforts.

**Discussion:** If such goals were set, it could serve as a rallying point for organ procurement organizations, and some of their professional training efforts could be built around these goals. Of course, there is a fine line between approaching such an effort in a humane and sensitive way on the one hand, and having it appear distasteful on the other. Such goal setting would have to be done with the greatest of care. However, there may be some justification for considering this since we know that there is significant organ wastage.

**ISSUE IX:** Increasing organ donation from among ethnic minority communities requires specific training for requestors which will enable them to approach the families of potential donors in a manner which will be culturally sensitive and appropriate.

**Discussion:** Among individuals needing organ transplants, there is a disproportionately high representation of individuals from ethnic minority groups and yet there is a lower than average rate of organ donation from members of racial and ethnic minority groups (30). The skills required in approaching an African American family, a Latino family, or Asian families from various national and religious backgrounds are different from the skills in approaching a Caucasian family. Therefore, the training of requestors must be tailored to developing the specific sensitivities which are required in approaching families from a variety of racial and ethnic backgrounds. In certain centers it may also be appropriate to recruit requestors from specific racial and ethnic backgrounds in an effort to improve the effectiveness of organ requests from ethnic minority groups.

## **Proposed Recommendations**

The authors would like to propose the following recommendations to the participants of the Surgeon General's Workshop on Organ Donation.

- 1.** That the Division of Organ Transplantation, with advice from the transplant community, prepare a plan for a national strategy to incorporate issues related to organ procurement and transplantation at all levels of physician, nursing, and allied health professions training programs. The preparation of this plan should enlist the participation of all relevant national associations of health professional training and relevant credentialing boards. The plan should address not only action steps, but also organizations and individuals who will be responsible for carrying out the action steps.
- 2.** That the Division of Organ Transplantation design studies which will seek to answer, among others, the following questions:
  - How do professionals' attitudes and knowledge correlate with public attitudes and knowledge as it relates to organ donation and transplantation, and what interventions might effectively influence perceived societal norms related to attitudes regarding organ donation and transplantation?
  - What comparisons can be made of the relative success of various modalities of training undergraduate medical students in issues related to organ donation and transplantation?
  - Which organ procurement organizations have been most successful in mobilizing the efforts of health professionals and are there any identifiable variables which can account for this success?
- 3.** That the Division of Organ Transplantation, calling upon other Federal Agencies and private sector organizations, design a program which will train key policy makers and elected officials at the State and national levels in the importance of increasing organ donation.
- 4.** That the Division of Organ Transplantation convene a working group of interested parties to consider better ways of "marketing" the services of OPOs and organ transplant coordinators to the health professional and hospital communities at large.
- 5.** That a study be conducted to determine the frequency and nature of litigation which has been brought against health care professionals in cases related to organ procurement and transplantation. The results of such a study could serve to allay

fears, or could provide useful guidance as to how to better fashion statutes in order to protect health care professionals.

6. That the Division of Organ Transplantation study the rates of organ procurement and the organ demand within the regions served by the OPOs, and develop realistic goals for organ procurement within these respective regions so that these goals can serve as rallying points for institutions and health care professionals within those regions.

7. That the Division of Organ Transplantation develop a contract request for proposals which will seek to identify attitudinal impediments among the various health care professionals to optimal organ donor procurement. This effort should also seek to propose means of overcoming these impediments through various training modalities.

8. That the organ transplant community explore improved means of training health professionals in the skills necessary to approach families of various racial and ethnic minority groups requesting organ donation.

9. That forums be sought to provide training in organ donation issues for the various professional groups not directly involved in organ donation, but whose roles place them in situations where they could influence organ donation, such as morticians, attorneys, medical examiners, and others.

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